

S1 File. Data Extracts

Extract 1. Hospice outpatient consultation with a male patient – diagnosed with neck tumour and lung metastases – and his brother companion.

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VERDIS31 15.13 VT310 EL31.2 MP line 15
Dr D
Time into the consultation: 14 min

01 Com:      You know when he (0.2) he' [s bad you know the pain
02 Doc:                                     [Mm.
03           (0.4)
04 Doc:      Y[eah.
05 Com:      [(A:n::')/(The:n::) (1.2) then his breathing
06           and everything goes.
07 Doc:      It's bad [altogether.
08 Com:      [And then he panics.
09 Doc:      Yeah.
10           (0.2)
11 Com:      Then he he has to have a (0.4) you know (i- uh the) (0.3)
12 Pat:      Inhale[r I have ↑it
13 Com:      [just-
14 Com:      just to
15 Doc:      Ye[ah.
16 Com:      [calm him [down.
17 Pat:      [Mm.
18 Com:      A[nd
19 Doc:      [Okay.
20 Com:      'n the[n
21 Pat:      [It's just (the) ↑cough it's just I can't
22           ↑cough (tch)
23 Doc:      ↑Sure
24           (0.6)
25 Pat:      So that calms me down. Then I'm okay I-
26           and then I have [medicine so .hhh[h
27 Doc:      [Mm. [Yeah.
28 Pat:      that will ( in) within half an hour,
29           so then I'll calm down.
30           (.)
31 Pat:      (Then) it's fine.
32           (0.3)
33 Doc: -> And when the pain's ba::d and you f-
34           -> start to feel a bit panicky,
35           -> .hhh can you- (0.2) can you remember
36           -> what's going through your mind [at that time?
               {Doc: circular hand gesture at the side of his own head}
37 Pat:      [fhhhhh ((= sigh))
               {Pat: lateral head shake}
38 Pat:      .hh It's just cough, (one (h)a) .hhh it's terrible.
39 Doc:      So cough cough cou[gh,
40 Pat:      [Cough cough cough.
41           .hhh And (0.2) .h
42 Doc: -> And what [you- what what you-]
43 Pat:      [(oh and) my e]yes goes
44           funny and .hhh I just (0.3)
45 Doc: -> What do [you think it's gonna happen?
46 Pat:      [I wa-
47 Doc: -> What's- [what are you thinking.
48 Pat:      [hhhh

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49 Pat: () hhhh (= sigh)
50 Doc: It's [difficult to (answer) ([)
51 Pat: [() hh [A very
52 rough tough time? Sometimes I feel like, (.)
53 .hhh "Oh (an') this is it now".
54 Doc: Awright.
55 Pat: .hh [('n I)
56 Doc: [Okay.
57 Pat: I mean I shouldn't b(h)e s(h)aying,
58 .hhh but sometime I do feel a:: (0.2)
59 .h[h
60 Doc: [Sometimes you won[der if this is it?]
61 Pat: [Yeah I'm just] wondering (a)
62 Doc: [Right?
63 Pat: [I feel like it's coming now it's coming.

Extract 2. Hospice day therapy consultation with a female patient diagnosed with severe heart failure and osteoporosis, and a past history of lymphoma. She is very short of breath.

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VERDIS16 00,01 VT1 EL16.1 MP line 186
Doctor D
Time into the consultation: 3.47 minutes

01 Pat:      It's not (0.5) a (0.9) a desperate
02           problem or anything like tha:[t.
03 Doc:                        [No:
04 Pat:      But we don't want it to get that way do [we so]: (0.8)
05 Doc:                        [Okay.  ]
06 Pat:      I'm just telling you tha:: (1.4) uh my mood
07           has dripped- (0.4) dropped a bit.
08           (0.8)
09 Doc: -> Do you think that's re- (.) that's (.) all around your
10 -> breathing getting wo:rse or (.) something else?
11 Pat:      tk If you wan'- (that) was fear. I think it's
12           just fear.           {Doc moves head towards the patient}
13           (.)
14 Doc:      Fear.           {Doc nods}
15           (0.2)
16 Pat:      Just fear.
17           (0.7)
18 Pat:      Just (0.2) the reality of knowing
19           what's happening a:n:' (0.2)
20 Doc:      °Right.°
21 Pat:      not being able to (0.7) ↑do anything about it.

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Extract 3. Hospice inpatient consultation with a male patient diagnosed with gastrointestinal stromal tumour.

VERDIS42 10,37 VT164 EL42.1 MP

Dr F

Time into the consultation: 6 minutes

01 Doc: Anything e:lse that (0.7) is kind of on your list
02 of (0.6) worries at the moment?

03 (0.6)

04 Pat: At the mome:nt?

05 (0.2)

06 Doc: Yeah.

07 (0.9)

08 Pat: U:::m: (1.7) my back pain.

09 (0.2)

10 Doc: Okay.

11 (0.7)

12 Pat: I don't know why it's come o:n.

13 (0.5)

14 Doc: Right.

15 (0.7)

16 Pat: It's a:ll down my spi:ne.

17 (0.2)

18 Doc: Yeah.

19 (1.4)

20 Doc: -> Have you had any thoughts about it?

21 (0.7)

22 Pat: Mainly (1.6) my gee pee, ((GP)) (1.3)

23 we:ll (0.3) I don't know,

24 (1.3)

25 Pat: what he's been doing.

26 (0.8)

27 Doc: Right.

Extract 4. From the same consultation as Extract 3 – male patient diagnosed with gastrointestinal stromal tumour.

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VERDIS42 12,31 VT214 EL42.2 MP
Dr F
Time into the consultation: 7.53

01 Doc:      So just (.) going back to you worrying about
02           your (0.3) back pain, (0.2)
03 Pat:      Mm mm.
04           (0.6)
05 Doc: ->   Are you able to share what's worrying you mo:st
06           (0.2)
07 Doc:      at the mo[ment?
08 Pat:      [Back pain.
09           (.)
10 Doc: ->   Mm:. But what about it.
11           (0.6)
12 Pat:      It's the absolute mu:rder.
13           (1.4)
14 Doc:      Okay.
15           (.)
16 Pat:      I wish it could go away.
17           (0.7)
18 Doc:      Okay.
19           (1.2)
20 Doc:      You said you're wondering <why> i:t's so ba:d,
21 Pat:      Yeah.
22 Doc: ->   Mm: (.) and have you had any thoughts
23 ->       as to why (0.9) it's so ba:d?
24 Pat:      No:
25           (0.6)
26 Pat:      Just came o:n.
27           (0.4)
28 Doc:      Okay.
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Extract 5. From the same consultation as extracts 3 and 4 – male patient diagnosed with gastrointestinal stromal tumour.

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VERDIS42 18,05 VT351 EL42.3 MP
Dr F
Time into the consultation: 13.28

01 Doc:      Do you have any sense in your mind (0.4)
02           what's happening with your (0.9)
03 Pat:      No:
04 Doc:      With your disease, with your tumour,
05           (0.4)
06 Pat:      No:.
07           (0.3)
08 Doc:      °Okay.°
09           (0.3)
10 Doc:      Is it something you think about?
11           (1.0)
12 Pat:      M::: a lot of the time, (2.6)
13           a lot of the time,
14 Doc:      °Okay?°
15           (1.0)
16 Doc:      And when you think about it, what do you think?
17           (1.3)
18 Pat:      I try and shut my mind off it.
19           (1.4)
20 Doc:      °°Okay? (Right.)°°
21           (1.1)
22 Pat:      I do:.
23           (0.7)
24 Doc:      °°Okay?°°
25           (1.7)
26 Doc:      And why do you think you do that?
27           (1.0)
28 Pat:      (Because I don't wanna) know about it.
29 Doc:      You don't want °(to know).°
30           (0.5)
31 Doc:      Okay.
32           (1.4)
33 Pat:      That's why:.
34           (0.4)
35 Doc:      O:kay.
36           (2.7)
37 Doc:      Okay.
38 Pat:      Don't wanna talk about it.
39           (.)
40 Doc:      °N:o.°
41           (1.0)
42 Doc:      Okay.
43           (1.4)
44 Doc:      HHHHH ((laugh))
45           (0.5)
46 Pat:      I'm a stubbo:rn (0.2) person?
47           (1.8)
48 Doc:      I think we a:ll (0.4) we all cope with our lot
49           in different ways don't we?=And
50           (0.3)
51 Pat:      hhh
52           (1.9)

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Supporting information to Pino M, Parry R, Land V, Faull C, Feathers L, and Seymour J (2016). Engaging terminally ill patients in end of life talk: How experienced palliative medicine doctors navigate the dilemma of promoting discussions about dying. *PLOS ONE*.

53 Doc: Okay.

Extract 6. From the same consultation as Extract 2 – female patient diagnosed with severe heart failure and osteoporosis, and a past history of lymphoma. She is very short of breath.

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VERDIS16 00,01 VT1 EL16.1 MP line 359
Doctor D
Time into the consultation: 8.30 minutes

01 Pat:      You know and I'm thinking and I'm saying to Michael, (.)
02           I said to Michael "(Oh) please (.) do- don't ge:t upset
03           I'm just telling you this is how it †i:s"
04           (0.3)
05 Doc:      Ye:s.
06           (0.6)
07 Pat:      "Thiss (0.5) is nothing you can do
08           about i[t,
09 Doc:      [Okay.
10 Pat:      you just live with i::†:t"
11           (0.6)
12 Doc: -> But you think- so coming back to what
13           -> you were saying befo:re for a second Lynn,
14           -> part of it is the fear of (0.3) what might happen?
15 Pat:      .hhh I'm I'll be honest
16           [I've ] never been frightened of dying,
17 Doc:      [(Yeah.)]
18 Doc:      No.
19 Pat:      .hhh until juss lately.
20 Doc:      Right.
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Extract 7. Hospice day therapy consultation with a male patient diagnosed with motor neurone disease.

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VERDIS02 07,48 VT61 EL02.2 MP
Dr A
Time into the consultation: 6.30 minutes

01 Pat:      I d- cuz I d- I don't know whether it's worth carrying on
02           taking (any) pills, as well, and just sit here.
03           (0.2)
04 Doc:      Mm:. {Doc nods}
05           (0.5)
06 Pat:      And um
07           (1.1)
08 Doc: -> You mentioned about a feeling of (0.3)
09           -> throwing in the ↑towel
10           (0.4)
11 Pat:      Yeah stop taking the pills
12           and stuff like that iss (0.2)
13 Doc:      S↑top ↓taking the pills.=
14           =[That's what you mean] by [that?
15 Pat:      =[Yea:::h ] [Yea:::~::~::[:h.
16 Doc:      [O↑kay

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Extract 8. From the same consultation as Extract 7 – male patient diagnosed with motor neurone disease.

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VERDIS02 24,44 VT234 EL02.3 MP
Dr A
Time into the consultation: 23 minutes

01 Doc:      Do you feel anxious about things Ian?
02           (0.6)
03 Pat:      Um (4.2) to tell you the truth al t- a- al ne1ver (0.4)
04           t1lk right, (0.2) (↑it) (er-) (1.0)
05           (it er hhh) (.) No I suppose al ne1ver .hhh
06           not for a while [and um (3.4) I think (1.1)
07 Doc:      [(Mm) {Doc nods}
08 Pat:      when Bill died hhhh,
09 Doc:      ↑Mm {Doc nods}
10           (1.0)
11 Pat:      I think tha- put- brought everything
12           back home you know?
13           (.)
14 Doc:      ↑Mm {Doc nods}
15           (0.7)
16 Pat:      Um
17           (2.9)
18 Pat:      As it seems so unexpected as we::[ll.
19 Doc:      [↑M::m {Doc nods}
20 Pat:      .ksHHH (0.3) t1lk and that (1.6)
21           and=hh (2.2) hhhh (0.3) don't know.
                {Pat: slight lateral head shake}
22 Doc: -> Did it make you th- think about you. hh
23 Pat:      YEA:::h. [Yeah it did at the time,=
24 Doc:      [Mm
25 Pat:      = a- .hh before all that (0.4)
26           you know I thought we::ll you're going to die
27           one day (this and [that but)
28 Doc:      [Mm mm.
29           (0.5) {Doc nods}
31 Pat:      You know (↑i) but- (1.0) but now um (1.9)
32           I thin- I do think more of it,

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Extract 9. Hospice outpatient consultation with a male patient diagnosed with pulmonary fibrosis, and his wife.

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VERDIS23 37,35 VT891 EL23.5 MP ((audio only))
Dr F
Companion: patient's wife
Time into the consultation: 33.20 minutes

01 Com:      He mainly stays in the car (don't you?)
02           (0.3)
03 ????:     (Okay,)
04           (1.0)
05 Doc:      Okay.
06           (0.3)
07 Doc:      .hhhhhhhhhhh (0.4) Um (.) you said you turn things
08           over a bit at night. But you're not (0.2)
09           really thinking that that's keeping you awake,
10 Pat:      Mm
11 Doc:      In the day do you (.) do you worry about things?
12           -> Do you- you- you- you mentioned about the (0.2)
13           -> the cyanosis and (.) and also the oxygen, .hhh (.)
14           -> um (1.5) you've heard what (.) doctor Fairclough
15           -> sai[d,
16 Pat:      [Mm.
17           (0.4)
18 Doc:      -> you've had that (0.4) um pirfenidone, and it didn't (0.2)
19           -> didn't (.) do [much and you're off it,
20 Pat:      [Yeah.
21 Doc:      -> .hhhh (0.7) do you worry about (0.9) what's coming?
22           (0.5)
23 Pat:      tk U::m:: (1.0) n::=no not really.
24           (1.3)
25 Pat:      It's jus- (0.8) how how far along the line
26           I'm going to go before (0.4) I get to that h
27           (0.2)
28 Com:      M[m
29 Doc:      [Okay.
30 Pat:      yeah breathing wise, am I (0.6)
31           you know (0.3) >gonna be at a point where< (0.6)
32           I'm (0.7) really really struggling,

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Extract 10. From the same consultation as Extract 1 – male patient diagnosed with neck tumour and lung metastases, and his brother.

VERDIS31 EL31.3 27.16 VT482 MP line 135
 Dr D
 Companion: patient's brother
 Time into the consultation: 28 minutes

((The patient has been talking about a clinical trial in which he hopes to enrol. He refers to this at line 2))

01 Pat: I don't know what they're going to do.
 02 .hhh But they are gonna call me.
 03 (0.4)
 04 Doc: O[kay].
 05 Pat: [only if they get everything there.
 06 Doc: -> Okay. So that's one (ha-) that's one thing
 07 -> is hoping that the Royal will have
 08 -> treatment [that'll work,]
 09 Pat: [Yeah.
 10 Com: [(Yeah.)]
 11 Doc: -> .hh[hhh do you ever wonder what will happen=
 12 Com: [Yeah.
 13 Doc: -> =if they don't have treatment that works?
 14 Pat: (hho) No:..
 15 Doc: 'Cause you [said
 16 Pat: [(It's a long waiting there,)
 17 Doc: ↓Yeah
 18 Pat: There is nothing ↑else
 19 (.)
 20 Doc: No.
 21 Pat: .hhh [They have been very] honest. =
 22 Doc: [(An') you said some-]
 23 Pat: = There's nothing ↑else
 24 Doc: No.
 25 Pat: .hh because eh (t-t-ay) you guys
 26 gave me a lot of (0.3) .hhh chemo:,
 27 and there is nothing e- (.) mo:re [chemo =
 28 Doc: [No.
 29 Pat: = you guys can give me?
 30 Doc: [No.
 31 Pat: [.hhhh Radiotherapy:
 32 last time he said "I won't give you anymore",
 33 but he .hhh luckily gave me one mo:re, (.)
 34 Doc: ↑Mm
 35 Pat: just to (0.3)
 36 Doc: ↑Mm
 37 (0.3)
 38 Pat: Yeah it's a long wait now,
 39 (a)hhh I've [got no i]dea what
 40 Doc: [(It's a long wait)]
 41 Doc: Mm [↑mm
 42 Pat: [.hh and one thing is (0.6)
 43 I'm getting worse.
 44 Doc: Ye:s.
 45 (0.3)
 46 Pat: So: my mind plays up a little bit,
 47 Doc: [Mh.
 48 Pat: [() I hope it's not (.)
 49 my time y↑et hah.

50	Doc:	Y↑eah
51		(0.2)
52	Pat:	Be[ing very honest,
53	Doc:	['Cause you-
54	Doc:	'Cause you said when the coughing was bad,
55		sometimes you wonder [if it might be then?]
56	Pat:	[Oh yeah. (It comes)]
57	Pat:	(You know that whe) .hhh When the coughing
58		is <u>really</u> bad, it's [just (0.7)
59	Doc:	[Mh,
60	Pat:	hh I think about i(t) (a)hh
61		.hhh[hh sometimes you don't wanna think about it
62	Doc:	[Mm.
63	Pat:	but it just ↑comes